# The Clinical Assessment of Concerning Sexual Behaviour

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# CHAPTER I

## CONTEXT OF CURRENT RESEARCH

Individuals with an intellectual disability have historically had their individual rights to sexuality denied, and were frequently considered to be dangerously promiscuous, leading to institutionalisation or compulsory sterilisation (Murphy & O'Callaghan, 2004). Due to the fear of them reproducing, they were also considered to be a significant burden on society and as a result, segregation was considered the safest position (McCabe, 1999). Furthermore, when the sexuality of those with intellectual disabilities is discussed many people still have feelings of discomfort (Szollos & McCabe, 1995). Consequently, people with intellectual disabilities are often marginalised and typically have limited or no access to suitable sex education across various settings, including at school and at home (Barron, Hassiotis, & Banes, 2004). These factors have negatively affected people with intellectual disabilities in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behaviour (American Association on Intellectual and Developmental Disabilities, 2013) and have prevented the development of appropriate socio-sexual knowledge.

People with intellectual disabilities experience the same need and desire to develop relationships, have sexual connections, and gain sexual knowledge as do people without disability (Kelly et al., 2009). The rights of individuals with intellectual disabilities have become more recognised and respected in general (O'Callaghan & Murphy, 2007), including the right to lead sexually healthy and fulfilling lives (Kramers-Olen, 2016). Increased awareness of their sexual rights and increased sexual experiences of people with intellectual disabilities have resulted in increased concerning and abusive sexual behaviour. Concerning sexual behaviour occurs for reasons such as limited social experiences (due to marginalisation and institutionalisation), and the lack of opportunity to gain sexual knowledge of appropriate

sexual behaviour (Kramers-Olen, 2016). This may reflect both historical attitudes towards sexuality, in which those with intellectual disabilities were segregated and had their rights to sexuality denied and also the challenges people with intellectual disabilities experience in grasping the complexities of human sexual relationships.

Consequences of concerning sexual behaviour to the individual, the victim and the victim's family, and to the community and society at large can be serious (Michie et al., 2006). Adequate assessment of concerning sexual behaviour is key to ensuring safety. Assessment allows practitioners to distinguish between behaviour that has resulted from sexual naivety and that of sexual deviance. People with intellectual disabilities are often 'excused' for their concerning sexual behaviour (Thompson et al., 2016) due to an assumption that they did not hold adequate sexual knowledge and therefore did not know they were performing an illegal or harmful act. Existing research has focussed on whether people with intellectual disabilities have the capacity to consent to sexual relationships. In considering individual rights to engage in sexual experiences that are safe, it is also important to assess the ability of the individual to gain consent from potential sexual partners.

# THESIS OUTLINE

The context for the current study is the clinical assessment of people with an intellectual disability who have engaged in concerning sexual behaviour. Research aims include examining the assessment tools used internationally in the assessment of concerning sexual behaviour with an intellectual disability population, including examining a locally developed assessment tool, The Explore Sexual Knowledge Examination (ESKE). Particular focus is given to how well these tools assess a person's understanding of the need to gain consent from a potential sexual partner. The questions considered throughout the thesis are: Does the person with an intellectual disability understand the complexities and pivotal aspects of negotiating consensual sexual interactions; and how is this knowledge assessed by practitioners working in the field of intellectual disability and concerning sexual behaviour?

Chapter Two defines key terms used throughout the current study. A review of research about important factors that have impacted people with intellectual disabilities in the development and understanding of their sexuality will be reported. The review describes international and local tools used to assess concerning sexual behaviour in individuals with intellectual disabilities. Chapter Three describes the methodology, research design and data collection procedures for the current study, involving a survey of practitioners working in the field of intellectual disability and concerning sexual behaviour. Chapter Four presents the study's results. Interpretation of the findings and limitations, strengths and theoretical relevance of the current study are discussed in Chapter Five.

# CHAPTER II

## DEFINITIONS AND BACKGROUND

### Defining Intellectual Disability

Intellectual disability is a neurodevelopmental disorder with onset during the developmental period, which includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (American Psychiatric Association, 2013). Essential features of intellectual disability are deficits in general cognitive abilities such as reasoning, problem solving, planning and abstract thinking, as well as problems with academic learning (Baines et al., 2018). Deficits result in impairments in everyday functioning, such that people have problems with independence, communication, social participation and occupational functioning (Wehmeyer et al., 2008). Assessment and diagnosis of intellectual disability are determined by standardised testing of both adaptive and intellectual abilities, and intellectual disability is commonly defined by scoring more than two standard deviations below the population mean on tests of general intelligence (American Psychiatric Association, 2013). Traditionally, intellectual functioning is sectioned into several levels (World Health Organization, 2016), including: Mild Intellectual Disability, IQ between 50/55-70; Moderate Intellectual Disability, IQ between 35/40-50/55; Severe Intellectual Disability, IQ between 20/25-35/40; Profound Intellectual Disability, IQ below 20/25. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), has moved away from placing emphasis on IQ scores for determining severity and relies more on adaptive behaviour.

### Decision-Making Deficits

A fundamental deficit among those with intellectual disabilities is the capability to make informed decisions (Craigie et al., 2018). There is no universally accepted way to measure a person's capacity to make decisions (Eastgate, 2005), however competency has

generally been recognised in the ability to receive, comprehend, retain and recall information, integrate the information received and relate it to one's situation, evaluate benefits and risks and communicate one's choice to others (Devereux & Parker, 2006).

Respecting the rights of those with intellectual disabilities to live a life in which sexual needs and desires are met can pose considerable challenges (Parchomiuk, 2012). A conflict arises between supporting those with intellectual disabilities to develop their sexual identity and live sexually fulfilling lives, while also guarding against vulnerability, exploitation and abuse when cognitive impairment interferes with the ability to make informed decisions (Dukes & McGuire, 2009). Whilst it is recognised that determining capacity for sexual relationships is complex (Lyden, 2007), it is also pivotal in order to protect the safety, wellbeing and rights of those who are more vulnerable. Murphy (2003) examined existing research on decision-making capacity for sexual relationships in those with intellectual disabilities and found most research and policy about decision-making capacity has concerned consent to treatment, with much less consideration of capacity to consent to sexual relationships, and even less consideration of the capacity of persons with intellectual disabilities to understand the need to gain consent from prospective sexual partners.

## Defining Sexuality within an Intellectual Disability Population

Human sexuality refers to sexual thoughts, feelings and behaviours. It can be considered as physical expression, self-image, emotional development, social circumstances, sensuality, spirituality and personal identity (World Health Organisation, 2006). Sexuality represents a central aspect of what it is to be human, and in order to comprehend and explore sexuality, support is often required. As with other areas of learning, those with intellectual disabilities require additional support to understand relationships and to discover their sexuality (Kramers-Olen, 2016).

Only in the past two decades has qualitative research begun to consider the desires and views about sexuality of those with intellectual disabilities (Parchomiuk, 2102). Yet despite

legislation that recognises human rights for those with disabilities, many are still discriminated against and are not supported to gain the knowledge they need in order to realise and explore their sexuality (O'Callaghan & Murphy, 2007).

## Defining Concerning Sexual Behaviour with Examples of Child, Adolescent and Adult Concerning Sexual Behaviours in an Intellectual Disability Population

The term *concerning sexual behaviour* is used throughout the current study to refer to sexual behaviours that cause problems for the person with an intellectual disability and in some instances, to others in the community. Within existing research, the terms concerning sexual behaviours and sexually abusive behaviours are often used interchangeably, however, the focus of the current study is the examination of concerning sexual behaviour, which although it may involve contact (touch) behaviours, does not encompass behaviours such as rape (McLay et al., 2015).

The scope of concerning sexual behaviour is varied and includes both non-contact behaviours (exhibitionism, inappropriate sexual boundaries, grooming, voyeurism, preoccupation with sexual matters, and sexting or recording images of sexual acts) and contact (touching) behaviours (Hackett et al., 2016). Concerning sexual behaviours may involve behaviours that are entirely self-focused such as excessive masturbation, or behaviours that involve others in a non-consensual manner (McLay et al., 2015). These behaviours are considered unacceptable by society and may place others at heightened risk of harm. Sexual contact with anyone more vulnerable than oneself is deemed to be concerning sexual behaviour (Lockhart et al., 2009). Table 1 presents examples of concerning sexual behaviours, differentiated by children, adolescents and adults.

**Table 1**

*Examples of Child, Adolescent and Adult Concerning Sexual Behaviours*

| | Child | Adolescent & Adult |
|---|---|---|
| **Concerning Sexual Behaviours** | Preoccupation with sexual themes<br>Attempting to expose others' or own genitals<br>Sexually explicit conversations with peers<br>Precocious sexual knowledge<br>Single occurrences of peeping, exposing, obscenities, pornographic interest, frottage<br>Preoccupation with masturbation<br>Mutual masturbation/group masturbation<br>Simulating intercourse with dolls, peers and animals | Sexual preoccupation/anxiety<br>Polygamist sexual intercourse<br>Embarrassment of others with sexual themes<br>Pulling skirts up/pants down<br>Attempting to expose others' genitals<br>Chronic preoccupation with sexually aggressive pornography<br>Compulsive masturbation (esp. chronic)<br>Public masturbation<br>Obscene phone calls, voyeurism, peeping, exhibitionism or frottage |

## Defining Consent

The term *consent* in the current study refers to sexual consent or consent for sexual activity. Consent is when someone gives permission, approves, or says "yes" to a sexual act with another person (Eastgate, 2005). To be valid, consent must be freely given, and all parties must feel that they are able to say yes or no or to discontinue the sexual activity at any time. It is the responsibility of the person initiating the sexual act to obtain this permission (Lyden, 2007).

## Defining Evidence-based Assessment

Evidence-based assessment is guided by research and theory to determine the selection of constructs to be assessed for a specific assessment purpose, the methods and measures to be used in the assessment, and the manner in which the assessment process unfolds (Hunsley & Mash, 2007).

# REVIEW OF EXISTING RESEARCH

Prevalence rates of concerning sexual behaviour by people with intellectual disabilities continue to increase (Baines et al., 2018). A key goal of this chapter is to explore important factors that influence the development of sexual identity and sexual knowledge of individuals with an intellectual disability. Consequently, reasons why individuals with an intellectual disability may exhibit concerning sexual behaviour will be discussed. A further goal of this chapter is to examine the most widely used assessment tools used with people with intellectual disability and concerning sexual behaviour in existing research. Three assessment tools will be the focus: The Socio-Sexual Knowledge and Attitudes Tool - Revised (SSKAAT-R, Griffiths & Lunsky, 2003), the Assessment of Sexual Knowledge (ASK, Galea et al., 2004), and the General Sexual Knowledge Questionnaire (GSKQ, Talbot & Langdon, 2006). This section considers the ability of these three tools to assess understanding of consent in people with intellectual disabilities and people's understanding of "the rules" (legal aspects) of sexual behaviour.

## Human and Sexual Rights

Changes in government policy in the 1970s supported the notion of 'normalisation' for people with intellectual disabilities (Simpson, 2018), recognising that those with intellectual disabilities had a right to inclusion within the community (Wolfensberger & Tullman, 1982). Normalisation for those with intellectual disabilities continued to develop over several decades and the emergence of deinstitutionalisation followed, which provided increased awareness of the human rights of those with disabilities (Simpson, 2018). In New Zealand, people with disabilities are protected by The New Zealand Bill of Rights Act 1990 (New Zealand Human Rights Commission, 1990) and New Zealand has also endorsed the United Nations Convention on the Rights of Persons with Disabilities (Quinn, 2009). This serves to protect the

fundamental rights of those with disabilities, viewing people with disabilities as being active members of society. Judgement of sexual rights based on disability is unlawful (New Zealand Human Rights Commission, 1990). In 2016 the New Zealand Government revised the New Zealand Disability Strategy which had a focus on issues for people with disabilities across government to enable better support for disabled people to achieve their potential and to improve the lives of disabled New Zealanders and their families (Office for Disability Issues, 2016).

## Attitudes that Negatively Impact on the Exploration of Sexuality for those with Intellectual Disability

Sexuality is a central aspect of being human, yet health practitioners, families and caregivers frequently perceive romantic and intimate relationships for people with intellectual disabilities to be inappropriate (Kramers-Olen, 2016).

Many factors impact on the ability of people with intellectual disabilities to pursue their sexuality; some factors are external and pervasive, including discrimination, exclusion, and isolation within their communities (Dukes & McGuire, 2009). Reasons for the lack of support and disapproval from others are varied, however there is a global prejudice towards those with disabilities and an inference that they are perceived as less attractive partners, are asexual, and the most common stereotype, that they are eternal children with no need for support regarding the exploration of their sexuality (Parchomiuk, 2012).

Parchomiuk (2012) examined the attitudes of 98 specialists including social workers, nurses, special educators and physiotherapists towards sexuality within an intellectual disability population. It was found that specialists regarded marriage, sexual intercourse and having children to be unacceptable for people with an intellectual disability.

Young et al., (2012) conducted semi-structured interviews with caregivers of adults with intellectual disabilities working in residential homes. Caregivers were found to demonstrate conservative attitudes about the sexuality of those with intellectual disabilities

and to convey messages that sex and sexuality among people with intellectual disabilities are inappropriate or offensive. McGuire and Bayley (2011) conducted surveys of caregivers of people with intellectual disabilities and similarly identified restrictive and prohibitive attitudes among caregivers. The study identified that caregivers require education about the sexuality of those with intellectual disabilities, so they are in a better position to support the exploration of their sexuality. Cuskelly and Bryde (2004) assessed attitudes of parents and caregivers toward the sexuality of adults with intellectual disabilities using a questionnaire. The study found that parents of those with intellectual disabilities had more conservative views about sexuality than caregivers, however both parents and caregivers held negative attitudes about sexual behaviour of those with intellectual disabilities. Parents frequently considered that information about sexuality would make their child more likely to engage in sexual behaviours and consequently information was regularly withheld (Cuskelly & Bryde, 2004).

## Prevalence of Concerning Sexual Behaviour for People with Intellectual Disability

Estimates of intellectual disability in offender populations vary (Lindsay, 2011). Hayes (2002) found the prevalence of people with intellectual disabilities in prisons across Western Australia to be twenty percent. Murphy et al., (2000) found the prevalence of people within prisons in Ireland convicted of offences with an intellectual disability was twenty-eight percent (the study did not differentiate sexual offences from other types of serious offending). People with an intellectual disability are overrepresented in the criminal justice system (Hayes, 2002; Vanny et al., 2009; Michie et al., 2006). Fogden et al., (2016) examined databases from disability and mental health services and police records within Australia and found the estimated prevalence of offending by people with intellectual disabilities varied from two to ten percent. Prevalence within the prison population varied from two to thirty percent. The study concluded that rates of offending by those with intellectual disabilities are substantially

different from offending rates of the general population, and people with intellectual disabilities are overrepresented within the criminal justice system.

Lindsay (2002) reviewed existing research with individuals with intellectual disabilities who had been convicted of offences, including sexual offences. He reported that estimates of intellectual disability in offender populations varied between one and thirty-nine percent, and the prevalence of people with intellectual disabilities who had committed sexual offences varied between twenty-one and twenty-nine percent. Lindsay further reported that prevalence rates in prison populations are not an accurate reflection of the numbers of people with intellectual disabilities who have been charged with concerning sexual behaviour, due to people being diverted out of the criminal justice system. Furthermore, rates may be underrepresentions as many instances go unreported due to family members, residential providers and carers turning a blind eye to the offending (Lindsay, 2002; O'Callaghan & Murphy, 2007), often due to the person being perceived as not having adequate understanding of their concerning sexual behaviour (Lindsay et al., 2007; Emerson, 2001). Additionally, some cases are reported to the Police, but a decision is made not to investigate the incident further due to a perception that the person did not have an adequate understanding of their behaviour (O'Callaghan & Murphy, 2007).

Keeling et al., (2006) examined different risk assessment methods for sexual offenders with an intellectual disability and reported an overrepresentation of concerning sexual behaviours and sexual offending by people with an intellectual disability. The study labelled concerning sexual behaviour as an issue that needs to be addressed.

Almond and Giles (2008) examined case files from fifty-one people with an intellectual disability who had exhibited concerning sexual behaviour and a comparison group of fifty-one matched peers who had exhibited concerning sexual behaviour who did not have an intellectual disability. The study found there were more similarities than differences between the two samples. Similarities included victim characteristics (victim choices were similar in age, gender and relationship to the perpetrator) and offence characteristics (types of sexual

offences). A key difference noted in the study was that people with intellectual disabilities tended to engage in 'nuisance' sexual behaviours such as exposure and public masturbation more often (25% of the cases) than people without an intellectual disability (12% of the cases). Whilst the actual numbers of people engaging in sexually concerning or abusive sexual behaviours are not exact, there is consensus within existing research that the figures are high and concerning (Lindsay, 2002).

**Sexual Knowledge**

People with intellectual disabilities have a relatively low level of understanding and knowledge about sexuality, are inexperienced at dating and have fewer opportunities to learn about sexuality (McCabe, 1999; Cheng & Udry, 2002; Murphy & O'Callaghan, 2004). McCabe (1999) assessed the level of sexual knowledge of individuals with intellectual disabilities, physical disabilities and those without disabilities. Results showed that in all areas of sexuality assessed, people with intellectual disabilities demonstrated lower levels of sexual knowledge than people with physical disabilities, who in turn demonstrated lower levels of sexual knowledge than those without disabilities. Murphy and O'Callaghan (2004) examined the sexual knowledge and understanding of sexual abuse of adults with intellectual disabilities and a comparison sample without disabilities. People with intellectual disabilities lacked important information and knowledge in several key areas of sexual knowledge, including the understanding of consenting and non-consenting situations, and often did not recognise non-consenting situations as abusive.

Kramers-Olen (2016) reviewed existing research about the barriers preventing sexual expression for those with intellectual disabilities. A key barrier is that individuals with intellectual disabilities are often excluded from sexual education programmes and not provided with sexual knowledge from families, schools, care settings or support people. Insufficient discussion about sexual behaviour has been shown to result in insufficient knowledge, which impedes the ability of those with disabilities to establish their sexual identity and engage in safe sexual practices (Gougeon, 2009).

Schaafsma et al., (2017) conducted a study which involved the collaboration of people with intellectual disabilities in the development of a sexual education programme. The study assessed the perspectives of individuals with intellectual disabilities on several sexuality-related topics, including relationships and parenthood. Sexual and intimate relationships were found to be important for most participants. The study lends support to the inaccuracy of the notion that individuals with intellectual disabilities are asexual with limited needs for intimacy. A recent study by Baines et al., (2018) investigated the sexual activity of 527 people with mild-moderate levels of intellectual disability. Seventy five percent of male participants and 72% of female participants with intellectual disabilities had experienced sexual intercourse by age 19-20 and were likely to have had unprotected sex 50% more than their matched peers. They concluded that health and education services must expect that most young people with mild-moderate intellectual disabilities will be sexually active.

McCarthy and Thompson (1997) conducted a study of sexual abuse with 120 men and 65 women with intellectual disabilities. The study found that individuals with an intellectual disability have a compromised understanding of sexual consent and are more likely to be unable to distinguish abusive from non-abusive relationships.

Dukes and McGuire (2009) examined the sexual knowledge of people with a moderate intellectual disability by delivering a sexual education programme to participants twice weekly, for a 10-week period. They found that individually facilitated sexuality education programmes resulted in increased sexual knowledge, as well as improved capacity to make sexuality-related decisions for all participants, as measured by the Sexual Consent and Education Assessment (Kennedy, 1999). The concept that sexual education programmes are beneficial to those with disabilities and result in improved ability to accomplish sexually related decisions was supported by this study.

Recognition of the importance of sex education in the development of sexuality and safe sex practices for individuals with intellectual disabilities is beginning to be understood, yet education programmes are often limited and of low quality (Schaafsma et al., 2017). Schaafsma et al. interviewed individuals with intellectual disabilities following the delivery of

sex education programmes and found that sexual knowledge was mainly limited to topics such as safe sex, contraception and sexually transmitted infections. From semi-structured interviews, they found topics such as the legalities of sex, privacy and sexual boundaries, sex positivity, safe masturbation, consent, social media, sexual abuse, and the development of friendships and intimate relationships are often omitted from sex education programmes for people with intellectual disabilities and, consequently, those they interviewed during the study had gaps in their sexual knowledge across these areas. The provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realisation of sexual autonomy for people with intellectual disabilities and is essential in the complex negotiations required for consensual sexual interactions (Healy et al., 2009).

**Understanding the Law**

O'Callaghan and Murphy (2007) examined knowledge of the laws about sexuality among 60 participants with intellectual disabilities and a comparison group of 60 participants without intellectual disabilities. A questionnaire was developed to assess participants' understanding of sex and the law. They found only 25% of the adults with intellectual disabilities understood the age of consent, compared to 92% of those without an intellectual disability. Fewer than half of those with intellectual disability (43%) were aware that it was illegal to have sexual relationships with a minor, compared to 88% of those without an intellectual disability. Approximately half of the participants (48%) with an intellectual disability did not know that the laws prohibiting sexual assault and rape also applied to them (O'Callaghan & Murphy, 2007). This study's results suggest that ignorance of the law and the social rules surrounding sexual behaviour is related to concerning sexual behaviour.

**Social Vulnerability**

For persons with intellectual disability, the shift from institutional to community living provided several opportunities for community participation, social connectedness and inclusion (Fisher et al., 2015). Fisher et al. conducted a review of existing research to identify

all publications related to victimisation or social vulnerability of adults with intellectual disability. They found that while inclusion has led to more fulfilling lives for those with intellectual disabilities, it can also lead to them being victimised. Important risk factors for victimisation relate to the presence of intellectual disability and being socially vulnerable (particularly for those who have substantial deficits in interpersonal and communication skills), deficits in socio-sexual knowledge, having few friends or social supports, and environmental factors such as living in residential care services.

Living in the community does not mean those with intellectual disabilities have freedom of choice or social integration and inclusion (Duvdevany & Arar, 2004). Duvdevany and Arar interviewed 85 adults with intellectual disabilities living in various community settings and found persons with intellectual disability are often directed to live in particular environments and given little choice about their personal circumstances. The disability sector is one of few in which many adults live with other adults whom they haven't chosen often for the majority of their adult lives (Brown & Brown, 2009). People are often directed to live in residential homes with others who have intellectual disabilities; some of these homes have adequate support and safety, however many do not (Fisher et al., 2015). People with intellectual disabilities are at increased risk of being sexually victimised (Fisher et al., 2015). They may not have a way of communicating the abuse to others and may not understand that the abuse is illegal, or that they have a right to say no.

The two main categories of perpetrators who sexually abuse those with intellectual disabilities are residential staff and peers with intellectual disabilities who reside in the same home (Fisher et. al, 2015). The lack of social and sexual opportunity and subsequent isolation can increase the risk of persons with intellectual disabilities engaging in abusive or concerning sexual behaviour with their peers or housemates (Fisher et al., 2015). Due to high rates of social contact with others who have intellectual disabilities, by the virtue of residing with them, those with intellectual disabilities are more likely to have sexual experiences with others who also have an intellectual disability (Duvdevany & Arar, 2004). The problem arises when it is

not clear whether these sexual experiences were of a consensual nature (Schaafsma et al., 2017). This highlights the importance of ensuring that those with an intellectual disability can both provide and adequately obtain consent before engaging in sexual relationships.

## Consent

Much of the existing research about consent refers to the capacity of people with intellectual disabilities to give their consent (Murphy, 2013). Consent has largely been examined in the context of capacity to give consent to treatment and capacity of a person with an intellectual disability to consent to various health assessments (Murphy, 2013; Lyden, 2007). The extant research about consent for sexual activity is primarily from the position of a person's capability to give consent for sexual acts and does not focus on whether persons with intellectual disabilities understand the necessity of gaining consent from others.

Lyden (2007) appraised the assessment of capacity to consent to sexual activity amongst those with intellectual disabilities. He described that in order to be deemed capable of giving consent to engage in sexual activity, a person must show awareness that it is illegal to subject another person to sexual activity in any of the following circumstances: through forced coercion; if the other person lacks capacity to consent to sexual activity; and when the other person is under the legal age to enter a sexual relationship (in New Zealand this age is 16 years old, however this varies across countries and states). However, although Lyden's research identified a clinical standard for assessing capacity to give sexual consent, the study acknowledged there are limited assessment tools that measure this knowledge.

## Gaining Consent from a Potential Sexual Partner

Assessing whether persons with intellectual disabilities understand the complexities of negotiating consent for sexual acts prior to engaging in them is a very important matter and has been given little consideration within existing research. The question considered throughout the current study is: Does a person who has an intellectual disability know and understand the complexities and pivotal aspects of negotiating consensual sexual interactions,

and how is this knowledge assessed by practitioners working in the field of concerning sexual behaviour and intellectual disability?

# CLINICAL ASSESSMENT OF CONCERNING SEXUAL BEHAVIOUR IN PEOPLE WITH AN INTELLECTUAL DISABILITY

Over the past several decades, practitioners and researchers have begun to consider factors related to concerning sexual or offending behaviour of intellectually disabled populations (Lindsay, 2002). Practitioners have a central role in the assessment of concerning sexual behaviour. Adequate assessment tools that promote usefulness and usability and that support practitioners to generate quality information to support their work are central (Lyden, 2007). Superficially, persons with intellectual disabilities may have some understanding about consent for sexual acts, however if probed deeper, knowledge is often inadequate (O'Callaghan & Murphy, 2007). For example, an individual with an intellectual disability may be able to answer the question: "What is consent for a sexual act?", however if asked a further question such as: "What if the person initially says 'yes' and then changes their mind?" this may be beyond the person's level of understanding and knowledge. Alternatively, a person may appear to have limited sexual knowledge, however when asked in a manner that allows for verbal as well as visual responses (with the use of pictures and visual aids), the person may have a good level of understanding about the legalities of sexual acts and gaining consent. The capability of those working with individuals who have an intellectual disability to understand their level of understanding, through the use of assessment, is vital for ensuring safety and for determining the best treatment pathway and management of the concerning sexual behaviour. This chapter aims to review several of the most widely accepted psychometric tools used in this field.

## Existing Assessment Tools

Within clinical practice when assessing concerning sexual behaviour of people with intellectual disability, several widely accepted assessment tools are in existence. Three of the

most commonly reported assessment tools for assessing sexual knowledge are the Socio-Sexual Knowledge and Attitudes Assessment Test – Revised (Griffiths & Lunsky, 2003), the Assessment of Sexual Knowledge (Galea et al., 2004), and the General Sexual Knowledge Questionnaire (Talbot & Langdon, 2006). It is not clear whether these tools adequately assess a person's knowledge about the necessity of gaining consent prior to engaging in a sexual act, and a comprehensive evaluation of the tools is required. The current evaluation will look at the purpose of each of the assessment tools, and whether they assess a person's knowledge of consent comprehensively.

**The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R); Griffiths & Lunsky (2003):**

The SSKAAT was the first measure of sexual knowledge and attitudes designed for people with an intellectual disability (Lindsay, 2002). It was initially developed in the United States of America by Wish et al., (1979) and has been more recently revised by Griffiths and Lunsky (2003). The SSKAAT-R was established to provide a broad assessment of domains of socio-sexual knowledge and attitudes for use with people with intellectual disabilities.

The SSKAAT-R is intended to provide information about the sexual knowledge the person has. It is suitable for people who have limited verbal ability by allowing for non-verbal responses such as pointing at pictures and situations; however, it does require some verbal ability as many questions require a verbal response. The SSKAAT-R includes 370 questions and has seven knowledge subscales: (1) Anatomy, (2) Women's Bodies, (3) Men's Bodies, (4) Intimacy, (5) Pregnancy, Childbirth and Child-Rearing, (6) Birth Control and Sexually Transmitted Diseases, and (7) Healthy Boundaries. There are several questions that assess the person's attitudes about various sexual behaviours and the person is required to indicate approval or disapproval of such behaviours. These items are recorded as either 'correct' or 'incorrect', and therefore if respondents hold attitudes that differ from the developers, their score will be adversely impacted. The SSKAAT-R is comprehensive, and consequently it takes several hours to administer (and often several sessions, depending on the person's

concentration ability), plus an additional hour to score. The SSKAAT-R has been criticised by practitioners for being too lengthy to administer, and for failing to assess the participant's previous sexual history (McCabe, 1999). The tool is reported to have good internal consistency (Cronbach's alpha, .81 to .92), high inter-rater reliability (.89 to .96) and high test-retest reliability (.78 to .96; Griffiths & Lunsky, 2003). The SSKAAT-R can be used as a pre and post measure to assess for changes in sexual knowledge following the delivery of a sexual education programme.

Many of the pictures in the SSKAAT-R are sexually graphic and detailed (Galea et al., 2004). It has a sub-section about legal issues (within the healthy boundaries sub-test). It includes some pictures of illegal sexual touching (for example an adult touching a child's genitals) and asks questions such as "is it ok for an adult to touch a child in this way?" and consequences of this behaviour are explored. It does not assess the person's sexual history.

***Consent:***

The SSKAAT-R does not include a specific domain that assesses a person's understanding and knowledge of consent. The healthy boundaries sub-test includes questions that assess the understanding of legal consent (age appropriate sexual behaviour) and a picture that depicts a rape scene. Pictures of good and bad touching are presented and include a picture of two men shaking hands, a picture of a lady hugging a child and a picture of a man placing his hand on the outside of the clothing of another man's genitals. The participant is asked "is this a good or a bad way of touching?"

**Assessment of Sexual Knowledge (ASK); Galea et al., (2004):**

The ASK was established for individuals with intellectual disabilities in response to increasing research which indicated there are limited tools for assessing the sexual knowledge of people with intellectual disabilities (Galea et al., 2004). It was developed in response to increasing unsafe sexual behaviours among those with an intellectual disability (Galea et al., 2004). The ASK encompasses several domains of sexual behaviour and awareness and

includes a knowledge section, a section that assesses attitudes about sexual behaviours, and a concerning socio-sexual behaviours checklist, which is not intended for use in the assessment of sexual knowledge but can be used in response to concerning sexual behaviour. It principally assesses socio-sexual knowledge and sexual knowledge, but also assesses reasoning distortions specific to sexual offending behaviour. The knowledge section comprises 15 sections: (1) Parts of the Body, (2) Public and Private, (3) Puberty, (4) Menstruation, (5) Menopause, (6) Masturbation, (7) Relationships, (8) Protective Behaviours, (9) Sexuality, (10) Safer Sex Practices, (11) Contraception, (12) Pregnancy & Birth, (13) Sexual Health, (14) Sexually Transmitted Infections. and (15) Legal Issues about Sexuality.

The ASK encompasses black and white line drawings to assist in the assessment of a range of topics, however a study by Thompson et al., (2016) conducted a review of the ASK via semi-structured qualitative interviews with clinicians who use sexual knowledge assessment tools. Clinicians in the study expressed concern about the line drawings as they didn't provide much detail and the vagueness makes it difficult for those with intellectual disabilities to understand the content. More detailed photographs were proposed as a better option. A further criticism of the ASK is that the content is outdated and does not include domains that assess people's understanding of areas such as sexting and the internet (Thompson et al., 2016).

The ASK is reported to have good internal consistency (Cronbach's alpha, .83 to .99) and good test-retest reliability (.69 to .91; Galea et al., 2004). The ASK has not been available for purchase since 2017.

***Consent:***

The ASK contains a section that assesses the legal issues about sexuality. Within this section there is one specific question that asks for the definition of the word "consent". It also explores the legal age for sex and includes one question that queries who people can tell if they are touched in a sexual way by someone against their will and one question that asks about the understanding of rape.

### General Sexual Knowledge Questionnaire (GSKQ); Talbot and Langdon (2006):

The Bender Sexual Knowledge Questionnaire (BSKQ; Bender et al., 1983) was revised in 2006 by Talbot and Langdon, who subsequently developed the General Sexual Knowledge Questionnaire (GSKQ). The GSKQ is a measure of sexual knowledge developed for use with adults who have intellectual disabilities. It includes 63 items and consists of six sections: (1) physiology, (2) sexual intercourse, (3) pregnancy, (4) contraception, (5) sexually transmitted diseases and (6) sexuality. The GSKQ includes some pictures in the physiology section, however most of the measure uses a question and response assessment style and therefore requires participants to have verbal abilities. The GSKQ does not assess the person's previous sexual history.

The GSKQ is straightforward to administer and is relatively brief compared to other assessment tools, taking approximately thirty minutes. The GSKQ is an assessment of sexual knowledge and does not measure socio-sexual knowledge or the social skills required when engaging in sexual experiences with others, nor does it assess attitudes about sexual activities. The tool is reported to have high internal consistency (Cronbach's alpha, .94), and good split-half reliability (Cronbach's alpha, .80; Talbot & Langdon, 2006).

#### *Consent:*

The GSKQ does not assess consent, nor does it assess the understanding of consent or the legalities of sexual activity.

### Explore Sexual Knowledge Examination

The Explore Sexual Knowledge Examination (ESKE) was developed by clinicians within Explore Specialist Advice New Zealand (Explore). Explore is a national provider of specialist behaviour support to people with disabilities. Explore staff work with people who have challenging behaviours that impact on their ability to take part in their community, or who pose a risk to their own or others' safety (Explore Specialist Advice, 2016).

Explore regularly receives referrals for people who have exhibited concerning sexual behaviour. It is important in these situations, that the behaviour is assessed adequately in order to determine whether the person engaged in the behaviour as a result of inadequate knowledge about social norms and the legality of sexual behaviours, or whether the person knew they were committing an offensive act and were knowingly exhibiting sexually abusive or deviant sexual behaviour. If it is determined the person engaged in concerning sexual behaviour due to insufficient knowledge they are managed within the disability sector whereas if the assessment identified the behaviour was due to sexual deviance they are referred to the criminal justice system for treatment and the management of their offending behaviour.

The ESKE was developed out of clinical need within Explore and assesses concerning sexual behaviours, whereas several of the most widely accepted assessment tools target sexual knowledge more generally. The ESKE was created by senior practitioners and was developed for practitioners working with those with intellectual disabilities. The ESKE encompasses domains of sexual behaviour including legal issues, consent, public and private sexual behaviour, good and bad touch, pornography use, court processes and emotions. It also encompasses a risk screen that assess the presence of risk factors such as sexual interest in children, history of concerning sexual behaviour, criminal history, interpersonal relationship problems, emotion dysregulation, hostility, impulsivity, poor problem-solving skills and lack of co-operation with remediation attempts. The ESKE does not include general sexual knowledge questions such as those relating to body parts, contraception or menstruation. Practitioners select the sections that apply to the client, thereby reducing the time it takes to administer the tool. Aspects of existing tools that were considered the most useful and relevant to the assessment of concerning sexual behaviour were used in the ESKE, with permission from the authors.

The ESKE is a clinical measure used at the beginning of Explore's involvement with clients to obtain information about clients' concerning sexual behaviours and associated level of risk and to identify targets for intervention, including possible referral to a specialist Sex

Offender Treatment Programme. The assessment includes evaluating whether the concerning sexual behaviour was due to lack of knowledge or more serious causal mechanisms, including sexual deviance. The ESKE can be used as a pre and post measure to assess changes in sexual knowledge following the delivery of a sexual education programme. The ESKE has not been examined for reliability.

***Consent:***

The ESKE contains a section about consent, which has questions such as "What does consent mean?" and "When do you have to ask for consent?" It also queries what someone should do if a person says no to sexual touch. The ESKE also contains a comprehensive section (48 questions) about the legalities of sexual activity. There is a section on "The Rules" which further assesses consent and sexual knowledge through questions such as "Who are the groups of people it is never OK to have sex with or touch in a sexy way?", "Why is it not OK to have sex with or touch children under the age of 16 in a sexy way?" and "Why is it not OK to have sex with or touch in a sexy way people who can't say no?"

Domains assessed within each of the assessment tools are displayed in Table 2. The ESKE is the only assessment tool evaluated in the current study to assess the domain of consent. Note a 'tick' shows the domain has been addressed, however it does not indicate the domain has been assessed comprehensively.

**Table 2**

*Domains in Sexual Knowledge Assessment Tools*

| | Sexual Knowledge Assessment Tool | | | |
|---|---|---|---|---|
| Domain (of Tool) | SSKAAT-R | ASK | GSKQ | ESKE |
| Consent | × | ×[1] | × | ✓ |
| Legal Issues | ✓ | ✓ | ✓ | ✓ |
| Public/Private | ✓ | ✓ | × | ✓ |
| Relationships | ✓ | ✓ | × | ✓ |
| Sexual Intercourse | ✓ | ✓ | ✓ | ✓ |
| Pornography | × | ✓ | × | ✓ |
| Internet Use | × | × | × | ✓ |
| Masturbation | ✓ | ✓ | ✓ | ✓ |
| Risk | × | × | × | ✓ |

## Gaps in Knowledge

Existing research has suggested various explanations for why people with intellectual disabilities exhibit concerning sexual behaviours, including ignorance of the law (O'Callaghan & Murphy, 2007), difficulties with learning and retaining information (Aunos & Feldman, 2002), inadequate sex education training (McCabe, 1999), and inadequate information about emotional and psychological aspects of intimate relationships (Thompson, 2001). Although there is consensus that people with intellectual disabilities often have limitations or deficits in their sexual knowledge, this is not a sufficient explanation for the over-representation of concerning sexual behaviour among people with intellectual disability, as many people with

[1] There is one question which asks for the definition of consent, however, understanding and knowledge of consent is not explored beyond the definition.

gaps in sexual knowledge do not exhibit concerning sexual behaviour. There are many people with intellectual disabilities who have deficits in their sexual knowledge and who do not exhibit sexually concerning behaviours (Lunksy et al., 2007). Lunsky et al. assessed socio-sexual knowledge amongst individuals with intellectual disability who had a history of concerning sexual behaviour compared with a matched sample of individuals with intellectual disability and no known history of concerning sexual behaviour. The study found that people who had exhibited concerning sexual behaviour such as public masturbation or touching someone in a non-consensual manner did not differ in their sexual knowledge than matched non-offenders.

Thorough assessment of concerning sexual behaviour is extremely important in order to manage risk, victimisation and social vulnerability, and to identify treatment needs. A person who is assessed as exhibiting concerning sexual behaviour due to a lack of sexual knowledge is likely to be able to be helped with socio-sexual knowledge (Lindsay, 2011). If the assessment determines that adequate sexual knowledge is present, then this would suggest a more offending paradigm for treatment and management. The earlier evaluation of three widely accepted assessment tools' abilities to provide adequate information about the understanding of the legalities of sex, and of seeking consent prior to engaging in sexual activities among individuals with intellectual disabilities identified gaps in current research as well as limitations of these tools. The locally developed ESKE was developed in 2016 and has not undergone a process of review and evaluation. Thus, a comprehensive evaluation is required of the ESKE and of the three widely used international assessment tools used by practitioners who assess concerning sexual behaviours in individuals with intellectual disabilities.

**The Current Study**

In order to evaluate the clinical assessment of concerning sexual behaviour an online questionnaire was developed. The aim of the questionnaire was to establish the assessment methods that practitioners are using currently in their clinical practice, when assessing

concerning sexual behaviour in individuals with an intellectual disability, and to establish whether these methods are meeting the assessment needs of practitioners. A further objective of the questionnaire was to compare the strengths and limitations of three existing assessment tools widely used in this field, the SSKAAT-R, the ASK and the GSKQ, with the locally developed ESKE. Comparative studies of tools that assess sexual knowledge have not been conducted (Talbot & Langdon, 2006). Of particular interest was how consent and the legal aspects of sexual engagement are assessed, and whether the most widely accepted assessment tools for assessing sexual knowledge in people with intellectual disabilities adequately assess sexual knowledge.

The questionnaire utilised both quantitative and qualitative methods to understand the views of practitioners working in this area of clinical practice about concerning sexual behaviour.

# CHAPTER III

## METHODOLOGY

### Participants

Participants in the current study were practitioners who had previously worked or are currently working with people with an intellectual disability, including those working with people who had exhibited concerning or harmful sexual behaviour. Practitioners with experience using psychometric tools that assess concerning sexual behaviour of people with an intellectual disability were eligible to complete a questionnaire survey. Participants who did not have experience in the use of psychometric assessment tools were asked to specify the assessment strategies they employ, and to state their rationale for not using formal psychometric assessment tools in their assessment of concerning sexual behaviour, but these participants did not complete the full questionnaire survey. The number of participants without experience using psychometric assessment tools was 11. The number of participants who completed the full questionnaire survey was 74.

### Measures

A questionnaire was developed for the current study that participants completed online using Qualtrics Survey Software. The questionnaire contained twenty-nine self-report questions, including four demographic questions. Questions covered assessment strategies that practitioners working in the field of intellectual disability and concerning sexual behaviour may be using, including choice of psychometric tools. Four tools were focused on, the locally developed ESKE and the three other international measures: The SSKAAT-R; The ASK; The GSKQ.

Participants were asked to consider how well these four measures assess concerning sexual behaviour and how well the measures assess a person's understanding of the necessity

of gaining consent prior to engaging in sexual acts, using a five-point Likert type scale which ranged from “not very well” to “very well”. No information was collected about participants’ age, ethnicity and gender as they were not considered relevant to addressing the goals of the current research.

## Procedure

Approval to evaluate the ESKE and to invite employee practitioners to participate in the survey was granted from Explore Specialist Advice. Emails were also sent to managers of other services throughout New Zealand that assess or treat adults with an intellectual disability who have engaged in concerning sexual behaviour or sexual offending (e.g., Department of Corrections, STOP, WellStop), to request their support with the study by distributing the online survey to practitioners employed at their respective services. Participation in the survey was voluntary and anonymous.

Ethics approval was obtained from the University of Canterbury Human Ethics Committee (see Appendix C). One incentive was offered: Participants were offered the opportunity to go into a draw to win one of three $100 Westfield Mall vouchers. Participants were given the option of providing an email address if they chose to enter the prize draw, or if they wished to receive results of the study. Data collection was completed over a four-month period. The questionnaire took participants approximately 15 minutes to complete.

## Data Analyses

Preliminary analyses were conducted using the Shapiro-Wilk test to assess the normality of distributions. Descriptive statistics (means, SD, n, %) were calculated to ascertain the sample proportions for the four demographic variables: Professional identity, experience working with people with an intellectual disability (in years), experience working with people who have concerning sexual behaviour (in years), and proportion of participants’ roles that involve working with clients who have concerning sexual behaviour (in the past year).

Descriptive statistics were calculated to evaluate which psychometric tools practitioners reported using, features which determined their choices, how practitioners reported assessing consent within their assessments and how important they considered this aspect to be.

A Kruskal Wallis Test was calculated to assess the association between professional identity and the use of psychometric tools as an assessment strategy.

Spearmans rank order correlation coefficients were calculated to evaluate the association between psychometric tests as an assessment strategy and the professional identity and experience of practitioners. This was to identify if experience and professional training impact on the assessment strategy used by practitioners.

Non-parametric tests were used due to Shapiro-Wilk preliminary analyses of normality indicating distributions violated the assumption of normality.

Correlation analyses were also conducted to evaluate the associations between the different assessment strategies employed by participants to assess concerning sexual behaviours of their clients.

# CHAPTER IV

## RESULTS

Participants were 74 New Zealand based practitioners, whose professions included behaviour specialists[2] (34%), registered psychologists (29%), registered clinical psychologists (26%), registered applied behaviour analyst (ABA) psychologists (8%), and registered occupational therapists (3%). The level of professional experience working with people who have an intellectual disability ranged from fewer than two years (10%) to more than ten years (44%). Thirty three percent of participants reported more than ten years' experience assessing people who have intellectual disabilities and concerning sexual behaviour. Table 3 displays data for participants who provided demographic information.

Means and standard deviations for participants' responses to questions on the five-point Likert-type scale (with descriptors of never, occasionally, half the time, most of the time and always), asking which assessment strategies they use when assessing people for concerning sexual behaviour, and how often they employ each strategy are displayed in Table 4. For ease of interpretation, results are also presented in a dichotomous manner, where response options have been combined to indicate whether practitioners use the assessment method half the time or less, or more than half of the time. As can be seen in Table 4, clinical interviews with significant others and support staff were the most utilised assessment strategies, both with mean ratings of 4.32 ($SD$ = 1.11 and $SD$ = 0.99 respectively). Clinical interviews with clients were also an assessment method utilised frequently ($M$ = 4.04, $SD$ = 1.16), with 73% of the participants indicating they use this strategy more than half the time. Obtaining archival information (relying on historical reports and past assessments) was also

[2] Behaviour specialists are people with qualifications in psychology, speech and language therapy, occupational therapy, social work, and teaching, who use positive behaviour support models to deliver innovative and targeted behaviour support services in the disability sector.

a strategy used frequently (*M* = 4.01; *SD* = 1.88). The least common assessment method utilised was psychometric tools, with 36% of the sample using this strategy (*M* = 2.67; *SD* = 1.56).

**Table 3**

*Number and Percentage of People who Reported Experience Assessing those with an Intellectual Disability and Concerning Sexual Behaviour, and the Proportion of their Role this Work Encompasses for 39 Participants*

| Demographic Factors | *n* | *Percent* |
|---|---|---|
| Experience in Intellectual Disability | | |
| 0 - 2 years | 4 | 10 |
| 2 - 5 years | 9 | 23 |
| 5 - 10 years | 9 | 23 |
| 10+ years | 17 | 44 |
| Experience Assessing Concerning Sexual Behaviour | | |
| 2 years | 9 | 23 |
| 2 - 5 years | 7 | 18 |
| 5 - 10 years | 10 | 26 |
| 10+ years | 13 | 33 |
| Proportion of Role (in past year), Assessing People with Concerning Sexual Behaviour | | |
| < 50% cases | 26 | 67 |
| > 50% cases | 13 | 33 |

**Table 4**

*Means, Standard Deviations and Dichotomous Frequencies for Assessment Strategies used in the Assessment of Concerning Sexual Behaviour Reported by 74 Participants*

| | | Frequency | |
|---|---|---|---|
| Assessment Strategy | *M (SD)* | Half the Time or Less (%) | More than Half the Time (%) |
| Interview with Significant Other | 4.32 (1.11) | 13 | 87 |
| Interview with Support Staff | 4.32 (.99) | 12 | 88 |
| Archives (obtaining other records) | 4.01 (1.88) | 24 | 76 |
| Interview with Client | 4.04 (1.16) | 27 | 73 |
| Observations | 3.53 (1.29) | 43 | 57 |
| Psychometric Tests | 2.67 (1.56) | 64 | 36 |

Note: percentages were rounded to the nearest whole number

To evaluate associations between the various assessment methods used according to participants' responses to questions on the five-point Likert-type scales. Spearman's rank-order correlations were computed.

Table 5 summarises correlation coefficients among the different strategies employed by respondents to assess concerning sexual behaviour of their clients. Utilising psychometric tests was significantly positively correlated with conducting interviews with the client. Interviews with the client were also positively correlated with using archival material. Interviews with significant others were significantly positively correlated with interviews with support staff. Accessing archival material was significantly positively correlated with all assessment strategies, while making observations was correlated with interviews with support staff. Associations between the use of psychometric tests as an assessment method and conducting interviews with significant others and with support staff were not significant.

**Table 5**

*Correlations Among Strategies Used in the Assessment of Concerning Sexual Behaviour for 74 Participants*

| | 1. | 2. | 3. | 4. | 5. | 6. |
|---|---|---|---|---|---|---|
| 1. Interviews with Client | -- | | | | | |
| 2. Interviews with Significant Other | .22 | -- | | | | |
| 3. Interviews with Support Staff | .19 | .60** | -- | | | |
| 4. Psychometric Tests | .44** | .02 | .15 | -- | | |
| 5. Archives | .35** | .38** | .45** | .30* | -- | |
| 6. Observations | .04 | .16 | .48** | .20 | .42** | -- |

*Note:* *$p$<.05, **$p$<.01, two tailed.

Due to a key aim of the current study being to gain an understanding of how the use of psychometric tools are informing practitioners' assessments, it was of interest to examine practitioners' use of psychometric assessment tools, and whether differing amounts of clinical experience or differences in professional identity were associated with differences in the likelihood of using psychometric tools as an assessment method. A Spearman rank-order correlation was calculated to assess the association between years of experience and the frequency of use of psychometric tools. A significant positive correlation was found between the two variables, $r$ = .36, $p$ = .02. This indicates that the more experienced members of the sample reported more frequent use of psychometric tools in their assessments of clients with concerning sexual behaviour than less experienced practitioners.

A Kruskal Wallis Test was calculated to assess the association between professional identity and the use of psychometric tools as an assessment strategy. Results indicated that

there was no significant effect of professional identity on the use of psychometric tools, $X^2$ = .09, $p$ = .57.

Participants were asked to indicate whether they had used each of the four psychometric tools of interest. Opportunity was also given to list any additional psychometric assessment tools they have experience using. Of note, a small majority (55%) of those who reported using additional tools listed formal risk assessment psychometric tools such as the Stable 2007 and the Static-99R. While these tools can be used to guide assessments of people with an intellectual disability, they are used in the assessment of sexual offending as opposed to concerning sexual behaviour and are normed on a mainstream population and not an intellectually disabled one. Table 6 presents frequencies of experience with the various tools. The ESKE was the tool that the greatest proportion of the sample had experience using (22 participants). Participants also had considerable experience using the ASK (n = 21) and the SSKAAT-R ($n$= 17). Twenty participants reported that they did not have experience using any assessment tools to assess concerning sexual behaviour. These participants were not eligible to answer further questions in the survey given the subsequent focus on participants' views of the tools.

Figure 1 presents features reported by participants for determining why they chose particular psychometrics. Having access to the tool (21%) and the quality of assessment information the tool provides (21%) were the most endorsed reasons for choice. Expectations of participants' respective services (18%), ease of use (15%) and validation of the assessment tool (13%) were also important factors reported to impact choice. Training in the tool (4%) and familiarity with the tool (2%) were not commonly reported reasons for tool selection.

**Table 6**

*Proportion of the Sample who Reported Using each Psychometric Tool*

| Psychometric Tool | N |
|---|---|
| The General Sexual Knowledge Questionnaire | 9 |
| The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised | 17 |
| The Assessment of Sexual Knowledge | 21 |
| The Explore Sexual Knowledge Examination | 27 |
| Other | 19 |
| None: I have not used any assessment tools | 20 |

**Figure 1**.

*Features determining choice of psychometric tools*

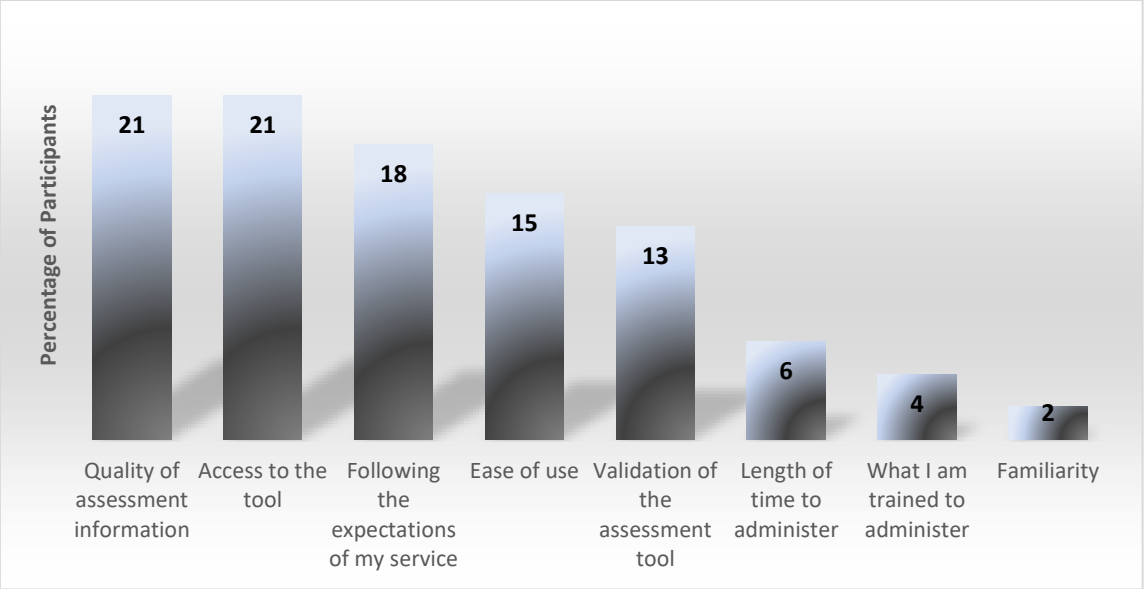


Figure 2 presents responses to questions about participants' assessment of their clients' knowledge about gaining consent, capacity to give consent, and understanding of the

legalities of sexual activity. Respondents indicated that they often assessed knowledge of gaining consent and capacity to give consent (63% of the respondents for these two domains). Assessing the legalities of sexual activity occured often by 53% of respondents, and frequently by 40% of respondents.

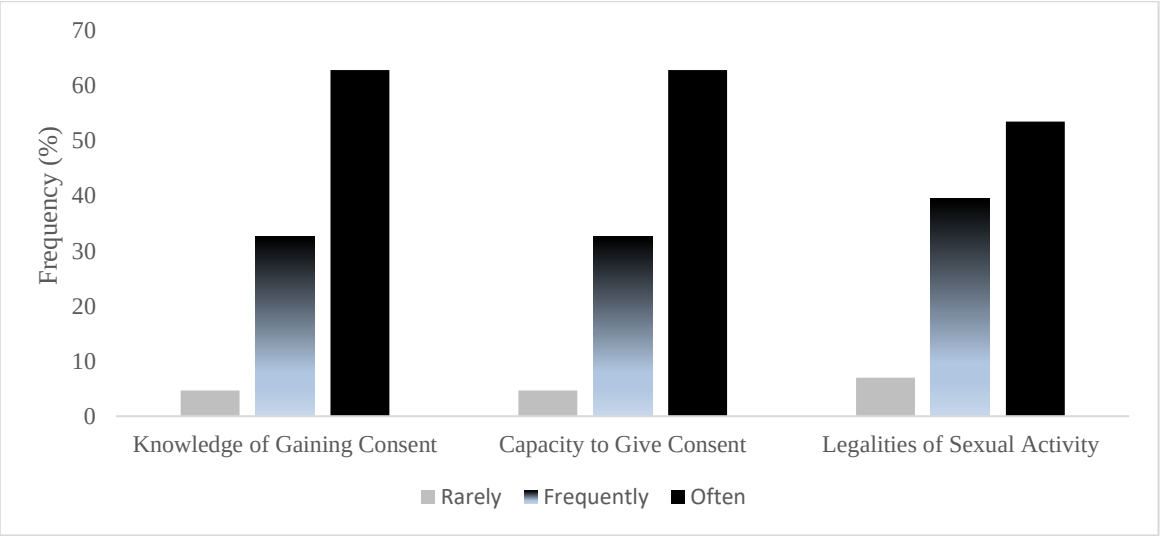


***Figure 2.***

Frequency Distribution of the Assessment of Knowledge of Gaining Consent, Capacity to Give Consent and Legalities of Sexual Activity

Respondents were asked to indicate ways psychometric tools were not meeting their needs as practitioners, if any, from a list of possibilities: 1. The language is confusing for clients. 2. It is not a validated tool. 3. It is too lengthy to administer. 4. The practitioner has not received adequate training in the tool. 5. The pictures are too explicit. 6. The content is too explicit. Respondents were given opportunity to describe other ways tools were not meeting their needs. Table 7 presents these results. Twenty three percent of respondents considered the pictures too explicit in the SSKAAT-R, whilst 8% of respondents considered this to be the

case in the ASK. No respondents considered the pictures to be too explicit in the GSKQ or the ESKE.

Across the four psychometric tools, a large proportion of respondents considered they had not received adequate training in the tools, particularly the GSKQ and the ESKE (33% for each of these tools). Respondents reported the biggest weakness of the ESKE was that it is not a validated tool (33% of the sample indicated this). Thirty three percent of respondents indicated they viewed the language of the GSKQ to be too confusing for clients, and 19% considered this to be true of the ASK. Both the SSKAAT-R and the ASK were thought to take too long to administer (20% and 23%, respectively).

**Table 7**

*Frequency Distribution of the Ways Psychometric Tools were Not Meeting Practitioners' Needs*

| | Psychometric Tool | | | |
|---|---|---|---|---|
| | SKAAT-R | ASK | GSKQ | ESKE |
| N (%) | | | | |
| Language too confusing for clients | 5 (17%) | 5 (19%) | 3 (33%) | 4 (15%) |
| It is not a validated tool | 0 (0%) | 2 (8%) | 0 (0%) | 9 (33%) |
| It is too lengthy to administer | 6 (20%) | 6 (23%) | 0 (0%) | 9 (33%) |
| Have not received adequate training | 5 (17%) | 5 (19%) | 3 (33%) | 9 (33%) |
| Pictures are too explicit | 7 (23%) | 2 (8%) | 0 (0%) | 0 (0%) |
| Content is too explicit | 5 (17%) | 1 (4%) | 1 (11%) | 0 (0%) |
| Other | 2 (7%) | 5 (19%) | 2 (22%) | 3 (11%) |

Note: percentages were rounded to the nearest whole number

Table 8 presents frequency information for the different assessment methods used by participants to assess a client's understanding of the necessity to gain consent from a potential sexual partner. The highest proportion of the sample (46%) reported using clinical interviews in their assessment of concerning sexual behaviour. Regarding participants' use of psychometric tools to inform their assessments, the tool most frequently used was the ESKE, with 28% of the sample reporting that they use this tool when assessing a client's understanding of the need to gain consent. The next most frequently used tool was the ASK, with 9% of the sample indicating they use this tool, while 3% of the sample indicated they use the GSKQ.

**Table 8**

*Frequency Distribution for the Assessment Methods Used to Assess a Person's Understanding of the Necessity to Gain Consent from a Potential Sexual Partner (n = 69 Participants)*

| | *Frequency* | |
|---|---|---|
| Assessment Strategy | N | *(%)* |
| Clinical Interview (with client and/or others) | 32 | (46%) |
| The General Sexual Knowledge Questionnaire | 2 | (3%) |
| The Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised | 4 | (6%) |
| The Assessment of Sexual Knowledge | 6 | (9%) |
| The Explore Sexual Knowledge Examination | 19 | (28%) |
| Other | 6 | (9%) |

Note: percentages were rounded to the nearest whole number

Table 9 displays respondents' reports about how well each of the tools assess a person's understanding of the need to gain consent from a potential sexual partner. Twenty two percent of participants considered the ESKE to assess this very well, and 5% of participants considered

each of the SSKAAT-R, the ASK and the GSKQ to assess this aspect very well. Twelve percent of participants indicated the SSKAAT-R did not assess this aspect very well, and 17%, 15% and 10% indicated the same of the ASK, GSKQ and ESKE, respectively.

**Table 9**

*Frequency Distribution of How Well Each Tool is Considered to Assess the Understanding of the Need to Gain Consent (n = 41 Participants)*

| | Not Very Well | Somewhat | Very Well |
|---|---|---|---|
| SSKAAT-R | 5 (12%) | 10 (24%) | 2 (5%) |
| ASK | 7 (17%) | 12 (29%) | 2 (5%) |
| GSKQ | 6 (15%) | 5 (12%) | 2 (5%) |
| ESKE | 4 (10%) | 11 (27%) | 9 (22%) |

Note: percentages were rounded to the nearest whole number

# CHAPTER V

## DISCUSSION

The present study examined the clinical assessment of people with an intellectual disability who have exhibited concerning sexual behaviour by investigating assessment methods used by practitioners in their clinical practice. Particular focus was given to how well three internationally used assessment tools and one locally developed assessment tool assess a person's understanding of negotiating consent from a potential sexual partner, and how practitioners assess this construct.

Major findings of the current study can be summarised as follows: There is a longevity of health practitioners working in the field of intellectual disability. Nearly half of participants who completed the study had more than 10 years of clinical experience with people with an intellectual disability. Prevalence of concerning sexual behaviour among those with an intellectual disability is substantial and rising (Lindsay, 2002), yet despite participants' extensive clinical experience, only one third of practitioners reported having experience in the assessment of concerning sexual behaviour.

Assessment strategies employed by participants to assess concerning sexual behaviour were evaluated. Psychometric tests were used as an assessment strategy less than half of the time by the majority of participants. This indicates that the sample used other methods of assessment over psychometric tools. This is an important finding as when assessments are conducted in this method it inhibits the assessment being guided by research and without the use of structured clinical assessment tools the assessment is at increased risk of being biased by the individual clinician. When psychometric tests were used by participants, the four assessment tools investigated in the current study were the most widely used, which is in line with existing research (Galea et al., 2004).

Primary assessment strategies used in the assessment of concerning sexual behaviour were interviewing support staff and interviewing significant others, with the majority of respondents opting to use these assessment approaches. These strategies were used more frequently than conducting clinical interviews with the person who had exhibited the concerning sexual behaviour. By omitting to conduct an interview with the person who has engaged in the concerning sexual behaviour, it cannot be determined what sexual knowledge the person has. Assessing the individual's sexual knowledge is part of ensuring safety and determining the best treatment pathway and management of the concerning sexual behaviour (Lindsay, 2011).

Associations among the various assessment strategies used by practitioners were examined to identify the connectedness of the various strategies. Those who used psychometric tests as an assessment strategy also routinely conducted clinical interviews with the client, whereas those who interviewed significant others and support staff often did not interview the client. These results indicate that practitioners often did not use a multimodal, multi-informant assessment method (Hanson & Thornton, 2000). This is important because accurate information is much more likely to be obtained through the use of a multimodal, multi-informant assessment strategy.

The current study examined what factors determined the choice of psychometric tools used by practitioners. Lack of training in the various assessment tools examined was a reason practitioners did not use some tools. Addressing this identified training need could enhance practitioners' clinical assessment and practice, reduce clinician bias and provide a more structured and scientific clinical method to the assessment of concerning sexual behaviour.

Although some tools that evaluate sexual knowledge do exist, it was of interest to determine whether the tools are meeting the needs of practitioners using them and the needs of those with intellectual disabilities. The current study revealed limitations with several of the existing, internationally accepted assessment tools, limitations which are in line with existing research (Galea et al., 2004; Griffihs & Lunsky, 2003). A limitation of all assessment tools

examined was that the language is too confusing for clients, most problematic for the GSKQ. With the exception of the GSKQ, the tools were all considered too lengthy to administer. This result is surprising in the ESKE, as this tool can be administered section by section, which reduces the overall administration time. A possible explanation for this result may be lack of training in the tool, which was reported by practitioners, such that they may not be aware of the ability to administer individual sections. Additional limitations of the SKAAT-R were that the pictures and the content are too explicit. The key limitation of the ESKE was that it is not a validated tool.

Whether the different assessment tools were able to assess whether a person with an intellectual disability understands the complexity of gaining consent from a potential sexual partner was central to the current project. Of the tools examined, the ESKE is the only tool that participants rated as adequately assessing consent. Participants indicated the importance of assessing consent and the legal aspects of sexual engagement and the participants indicated the assessment strategies most commonly used to support this were conducting clinical interviews with the client and/or significant others. The ESKE was the tool most often used to inform this assessment, despite most of the participants having experience with the other tools being evaluated. This lends support to the clinical utility of the ESKE. A substantial proportion of participants considered that the three international tools did not adequately assess consent.

## Implications of Findings and Future Directions

Practitioners working in the field of concerning sexual behaviour may feel uncomfortable assessing concerning sexual behaviour and can often feel burdened by the level of risk associated with the client (Boer et al., 2004). By reviewing how well the tools used in the assessment of concerning sexual behaviour performed, including the locally developed ESKE, practitioners will be better equipped to conduct structured clinical assessments. The ESKE was developed through a 'ground up' process, where expertise from practitioners experienced in the assessment of concerning sexual behaviour was sought, rather than a 'top down' theory and research driven process. The current project has contributed to improving

the assessment of concerning sexual behaviour by reviewing the ESKE in consideration of the extant research and the practitioners using it, and by contrasting it with other tools in existence. The current study provides support for the use of the ESKE as an assessment tool. Practitioners identified the current internationally accepted assessment tools are not adequate to assess important constructs of concerning sexual behaviour such as consent, and the language and content of the pictures do not meet the needs of those with intellectual disabilities. The current study also provides feedback to Explore, which may prompt Explore to refine the ESKE to ensure it meets clinicians' expectations and needs. Revising some of the language used in the tool to make it more accessible to those with intellectual disabilities would improve the tool.

The current study also highlighted the need for training for practitioners in the assessment of concerning sexual behaviour. It is important that training in the use of assessment tools is provided to practitioners so that practitioners working in this field conduct the assessment of concerning sexual behaviour in a manner which is evidence based and grounded in the scientist practitioner model of clinical practice (Hunsley & Mash, 2007). The current study revealed practitioners are conducting assessments in a manner that is often not informed by existing research as participants are frequently not utilising assessment tools to support clinical decision making. Conducting a clinical interview with the person who exhibited the concerning sexual behaviour, using behavioural observation of the individual and gaining alternative sources of information from collateral informants and archival information are all components of conducting a comprehensive assessment (Hunsley & Mash, 2007).

Findings of the current study have the potential to support processes for Explore Specialist Advice. When people are referred to Explore with concerning sexual behaviour it can be challenging to determine whether the referral should be actioned by Explore or by a specialist treatment service for sexual offending. The assessment information provided by the ESKE has the potential to assist in determining the appropriate treatment pathway and to

assist in ensuring safe management of the person who exhibited the concerning sexual behaviour.

Given the reported shortcomings of the assessment tools there is scope for refinement of existing tools so that the construct of consent is included. The current project established that the ESKE is the only tool examined that comprehensively assesses a person's knowledge of the complexity of negotiating consent. It also has additional and important constructs for assessing concerning behaviour that other tools do not include such as pornography use, which assesses a person's pornography behaviour, types of content viewed, search terms used, and assesses knowledge and access of child abuse imagery. Adjustments to the tools which include modifying the language and the content of the pictures so they are more accessible to those with varying degrees of intellectual disabilities will enhance the clinical utility of the tools.

Given the major limitation of the ESKE was that it is not a validated tool, psychometric research could be conducted to ensure validations such as face, predictive and construct validity of the ESKE.

The assessment of concerning sexual behaviour among those with an intellectual disability is an under researched field. Comparison studies of the evaluated tools have not taken place. Future research should focus on expanding the clinical utility of the ESKE as it is a tool which could be used beyond an intellectual disability population and could extend to the assessment of sexual knowledge of other populations of potentially vulnerable adults, for example those with a traumatic brain injury or dementia, and adolescents.

**Limitations of Research**

There are several limitations in the current study that must be considered when interpreting results. Although the current study recruited participants outside Explore, results may not generalise to other samples due to a likelihood that many participants were employed

within Explore's national organisation. Future research could adopt a different recruitment approach such as targeting samples affiliated with professional registration bodies.

The field of concerning sexual behaviour and intellectual disability is relatively specialised and therefore eligibility to participate in the study was limited and resulted in a limited sample size of participants.

The assessment of consent is not relevant for all forms of concerning sexual behaviour due to some concerning sexual behaviour not involving others, for example, public masturbation. Future research could collect more detailed information about the type of concerning sexual behaviour being assessed by practitioners.

## Conclusion

The current study examined how concerning sexual behaviour within the field of intellectual disability is assessed by practitioners in clinical practice. Results raise concerns over assessment strategies employed by practitioners in this field. Surprisingly, the use of assessment tools to inform assessments is an underutilised assessment method and not favoured by the majority of practitioners working in this area. Several reasons for the underutilisation of tools can be understood from the current study such as practitioner shortfalls in training to use assessment tools and limitations within the tools themselves. For example, many of the tools contain confusing language for clients and content that is too explicit.

The current study determined that the ESKE has clinical usefulness. Importantly, it was the only assessment tool that assessed a person's understanding of the complexity of negotiating consent, a construct which was deemed important by practitioners. It also has many additional benefits over other assessment tools, for example, the content and language of the tool are not explicit or confusing for clients (no participants in the current study indicated these constructs to be problematic). Training of practitioners in the assessment of concerning sexual behaviour was identified as a clear need, the addressing of which will improve the reliability of the clinical assessment of concerning sexual behaviour.

**REFERENCES:**

Abbott, D. (2013). Nudge, nudge, wink, wink: Love, sex and gay men with intellectual disabilities – a helping hand or a human right? *Journal of Intellectual Disability Research*, *57*(11), 1079-1087. https://doi.org/10.1111/j.1365-2788.2012.01642.x

Abbott, D., & Howarth, J. (2007). Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships? *Journal of Applied Research in Intellectual Disabilities*, *20*(2), 116-126. https://doi.org/10.1111/j.1468-3148.2006.00312.x

Almond, L., & Giles, S. (2008). Young people with harmful sexual behaviour: Do those with learning disabilities form a distinct subgroup? *Journal of Sexual Aggression*, *14*(3), 227-239. https://doi.org/10.1080/13552600802304909

American Association of Developmental and Intellectual Disabilities. (2008, November 08). *Sexuality*. https://www.aaidd.org/news-policy/policy/position-statements/sexuality

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).

Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *15*(4), 285-296. https://doi.org/10.1046/j.1468-3148.2002.00135.x

Baines, S., Emerson, E., Robertson, J., & Hatton, C. (2018). Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health*, *18*(1), 667-668. https://doi.org/10.1186/s12889-018-5572-9

Barron, P., Hassiotis, A., & Banes, J. (2004). Offenders with intellectual disability: A prospective comparative study. *Journal of Intellectual Disability Research*, *48*(1), 69-76. https://doi.org/10.1111/j.1365-2788.2004.00581.x

Boer, D. P., Tough, S., & Haaven, J. (2004). Assessment of risk manageability of intellectually disabled sex offenders. *Journal of Applied Research in Intellectual Disabilities*, *17*(4), 275-283. https://doi.org/10.1111/j.1468-3148.2004.00214.x

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11-18. https://doi.org/10.1111/j.1741-1130.2008.00198.x

Cheng, M. M., & Udry, J. R. (2002). Sexual behaviors of physically disabled adolescents in the United States. *Journal of Adolescent Health*, *31*(1), 48-58. https://doi.org/10.1016/S1054-139X(01)00400-1

Craigie, J., Bach, M., Gurbai, S., Kanter, A., Kim, S. Y., Lewis, O., & Morgan, G. (2018). Legal capacity, mental capacity and supported decision-making: Report from a panel event. *International Journal of Law and Psychiatry, 62,* 160-168. https://doi.org/10.1016/j.ijlp.2018.09.006

Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability, 29* (3), 255-264. https://doi.org/10.1080/13668250412331285136

Debenham, L. (2017). Normalisation and Learning Disabilities. http://www.aboutlearningdisabilities.co.uk/normalisation-learning-disabilities.html.

Devereux, J., & Parker, M. (2006). Competency issues for young persons and older persons. In I. R. Freckelton & K. A. Petersen (Eds), *Disputes and dilemmas in health law, 54-76*. Federation Press.

Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, *53*(8), 727-734. https://doi.org/10.1111/j.1365-2788.2009.01186.x

Duvdevany, I., & Arar, E. (2004). Leisure activities, friendships, and quality of life of persons with intellectual disability: Foster homes vs community residential settings. *International Journal of Rehabilitation Research*, *27*(4), 289-296. https://doi.org/10.1097/00004356-200412000-00006

Eastgate, G. (2005). Sex, consent and intellectual disability. *Australian Family Physician*, *34*(3), 163-166. https://doi.org/10.1030/369554386768035

Emerson, E. (2001). *Challenging behavior. Analysis and intervention in people with learning disabilities*. Cambridge University Press.

Euser, S., Alink, L., Tharner, A., Van Ijzendoorn, M., Bakermans-Kranenburg, M., (2016). The prevalence of child sexual abuse in out-of-home care: Increased risk for children with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 29*(1), 83–92. https://doi.org/10.1111/ jar.12160

Explore Specialist Advice. (2016). Explore Behaviour Support. https://www.healthcarenz.co.nz/wp-content/uploads/2018/06/Explore-Specialist-Advice.pdf

Fisher, M. H., Baird, J. V., Currey, A. D., & Hodapp, R. M. (2015). Victimisation and social vulnerability of adults with intellectual disability: A review of research extending beyond Wilson and Brewer. *Australian Psychologist*, *51*(2), 114-127. https://doi.org/10.1111/ap.12180

Fogden, B. C., Thomas, S. D., Daffern, M., & Ogloff, J. R. (2016). Crime and victimisation in people with intellectual disability: A case linkage study. *BMC Psychiatry*, *16*, 170-184. https://doi.org/10.1186/s12888-016-0869-7

Galea, J., Butler, J., Iacono, T., & Leighton, D. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *29*(4), 350-365. https://doi.org/10.1080/13668250400014517

Gougeon, N. (2009) Sexuality education for students with intellectual disabilities, a critical pedagogical approach: Outing the ignored curriculum. *Sex Education*, *9*(3), 277-291. https://doi.org/10.1080/14681810903059094

Griffiths, D., Hingsburger, D., Hoath, J., & Ioannou, S. (2013). 'Counterfeit deviance' revisited. *Journal of Applied Research in Intellectual Disabilities*, *26*(5), 471-480. https://doi.org/10.1111/jar.12034

Griffiths, D., & Lunsky, Y. (2003). Sociosexual Knowledge and Attitudes Assessment Tool (SSKAAT-R). *Stoelting*.

Hackett, S., Holmes, D., & Branigan, P. (2016). Harmful Sexual Behaviour Framework: An evidence-informed operational framework for children and young people displaying harmful sexual behaviours. https://www.nspcc.org.uk/globalassets/documents/publications/harmful -sexual-behaviour-framework.pdf

Hanson, R. K., & Harris, A. J. (2000). Where should we intervene? Dynamic predictors of sexual offense recidivism. *Criminal Justice and Behavior*, *27*(1), 6-35. https://doi.org/10.11772F0093854800027001002

Hanson, R. K., & Thornton, D. (2000). Improving risk assessments for sex offenders: A comparison of three actuarial scales. *Law and Human Behavior*, *24*(1), 119-136. https://doi.org/10.1023/A:1005482921333

Hayes, S. C. (2002). Early intervention or early incarceration? Using a screening test for intellectual disability in the criminal justice system. *Journal of Applied Research in*

*Intellectual Disabilities*, *15*(2), 120-128. https://doi.org/10.1046/j.1468-3148.2002.00113.x

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*, *53*(11), 905-912. https://doi.org/10.1111/j.1365-2788.2009.01203.x

Hill Kennedy, C., & Niederbuhl, J. (2001). Establishing criteria for sexual consent capacity. *American Journal on Mental Retardation*, *106*(6), 503-510. https://doi.org/10.1352/0895-8017

Hunsley, J., & Mash, E. J. (2007). Evidence-based assessment. *Annual Review of Clinical Psychology*, *3*, 29-51. https://doi.org/10.1146/annurev.clinpsy.3.022806.091419

Keeling, J. A., Beech, A. R., & Rose, J. L. (2006). Assessment of intellectually disabled sexual offenders: The current position. *Aggression and Violent Behavior*, *12*(2), 229-241. https://doi.org/10.1016/j.avb.2006.08.001

Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted.' *British Journal of Learning Disabilities, 37*, 308-315. https://doi.org/10.1111/j.1468-3156.2009.00587.x

Kennedy, C. H. (1999). Assessing competency to consent to sexual activity in the cognitively impaired population. *Journal of Forensic Neuropsychology*. https://doi.org/10.1300/J151v01n03_02hology, *1*(3), 17-33.

Kramers-Olen, A. (2016). Sexuality, intellectual disability, and human rights legislation. *South African Journal of Psychology*, *46*(4), 504-516. https://doi.org/10.1177 /2F0081246316678154

Kristensen Whittaker, M., Brown, J., Beckett, R., & Gerhold, C. (2006). Sexual knowledge and empathy: A comparison of adolescent child molesters and non-offending

adolescents. *Journal of Sexual Aggression*, *12*(2), 143-154. https://doi.org/10.1080 /13552600600823621

Lambrick, F., & Glaser, W. (2004). Sex offenders with an intellectual disability. *Sexual Abuse*, *16*(4), 381-392. https://doi.org/10.1177/107906320401600409

Lindsay, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, *46*, 74-85. https://doi.org/10.1046/j.1365-2788.2002.00006.x

Lindsay, W. R. (2011). People with intellectual disability who offend or are involved with the criminal justice system. *Current Opinion in Psychiatry*, *24*(5), 377-381. https://doi.org/10.1097 /YCO.0b013e3283479dc9

Lindsay, W. R., Hastings, R. P., Griffiths, D. M., & Hayes, S.C. (2007). Trends and challenges in forensic research on offenders with intellectual disability. *Journal of Intellectual & Developmental Disability*, *32:*(2), 55-61. https://doi.org/10.1080 /13668250701378520

Lockhart, K., Guerin, S., Shanahan, S., & Coyle, K. (2009). Defining "sexualized challenging behavior" in adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 293–301. https://doi.org/10.1111/j.1741-1130.2009.00235.x

Lunsky, Y., Frijters, J., Griffiths, D. M., Watson, S. L., & Williston, S. (2007). Sexual knowledge and attitudes of men with intellectual disability who sexually offend. *Journal of Intellectual and Developmental Disability*, *32*(2), 74-81. https://doi.org/10.1080 /13668250701408004

Lyden, M. (2007). Assessment of sexual consent capacity. *Sexuality and Disability*, *25*(1), 3-20. https://doi.org/10.1007/s11195-006-9028-2

McCarthy, M., & Thompson, D. (1997). A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities*, *10*(2), 105-124. https://doi.org/10.1111/j.1468-3148.1997.tb00012.x

McCabe, M. P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, *17*(2), 157-170. https://doi.org/10.1023/A:1021476418440

McGrath, R. J., Livingston, J. A., & Falk, G. (2007). A structured method of assessing dynamic risk factors among sexual abusers with intellectual disabilities. *American Journal on Mental Retardation*, *112*(3), 221-229. https://doi.org/10.1352/0895-8017

McGuire, B. E., & Bayley, A. A. (2011). Relationships, sexuality and decision-making capacity in people with an intellectual disability. *Current Opinion in Psychiatry*, *24*(5), 398-402. https://doi.org/10.1097/YCO.0b013e328349bbcb

McLay, L., Carnett, A., Tyler-Merrick, G., & van der Meer, L. (2015). A systematic review of interventions for inappropriate sexual behavior of children and adolescents with developmental disabilities. *Review Journal of Autism and Developmental Disorders*, *2*(4), 357-373. https://doi.org/10.1007/s40489-015-0058-5

Michie, A. M., Lindsay, W. R., Martin, V., & Grieve, A. (2006). A test of counterfeit deviance: A comparison of sexual knowledge in groups of sex offenders with intellectual disability and controls. *Sexual Abuse: A Journal of Research and Treatment*, *18*(3), 271-278. https://doi.org/10.1177%2F107906320601800305

Murphy, G. H. (2003). Capacity to consent to sexual relationships in adults with learning disabilities. *Journal of Family Planning and Reproductive Health Care*, *29*(3), 148-149. https://doi.org/10.1783/147118903101197520

Murphy, M., Harrold, M., Carey, S., & Mulrooney, M. (2000). A survey of the level of learning disability among the prison population in Ireland. *A Report for the Department of Justice, Equality and Law Reform, Dublin*. https://www.iprt.ie/site/assets/files/5983/learning_disability_report.pdf. https://doi.org/10.21427/D73729

Murphy, G. H., & O'Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine*, *34*(7), 1347-1357. https://doi.org/10.1017/S0033291704001941

New Zealand Bill of Human Rights Act 1990. http://www.legislation.govt.nz/act/public/1990/0109/latest/whole.html

O'Callaghan, A. C., & Murphy, G. H. (2007). Sexual relationships in adults with intellectual disabilities: Understanding the law. *Journal of Intellectual Disability Research*, *51*(3), 197-206. https://doi.org/10.1111/j.1365-2788.2006.00857.x

Office for Disability Issues (2016). https://www.odi.govt.nz/

Parchomiuk, M. (2012). Specialists and sexuality of individuals with disability. *Sexuality and Disability*, *30*(4), 407-419. https://doi.org/10.1007/s11195-011-9249-x

Penny, R. E. C., & Chataway, J. E. (1982). Sex education for mentally retarded persons. *Australia and New Zealand Journal of Developmental Disabilities*, *8*(4), 204-212. https://doi.org/10.3109/13668258209018763

Quinn, G. (2009). The United Nations Convention on the Rights of Persons with Disabilities: Toward a new international politics of disability. *Texas Journal on Civil Liberties & Civil Rights, 15*(1), 33–52.

Schaafsma, D., Kok, G., Stoffelen, J., & Curfs, L. (2017). People with intellectual disabilities talk about sexuality: Implications for the development of sex education. *Sexuality and Disability*, *35*(1), 21-38. https://doi.org/10.1007/s11195-016-9466-4

Siebelink, E. M., De Jong, M. D., Taal, E., & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: Assessment of knowledge, attitudes, experiences, and needs. *Mental Retardation*, *44*(4), 283-294. https://doi.org/10.1352/0047-6765(2006)44

Simpson, M. K. (2018). Power, ideology and structure: The legacy of normalization for intellectual disability. *Social Inclusion*, *6*(2), 12-21.

Swango-Wilson, A. (2008). Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality and Disability, 26*(3), 167-174. https://doi.org/10.1007/s11195-008-9081-0

Szollos, A. A., & McCabe, M. P. (1995). The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers. *Australia and New Zealand Journal of Developmental Disabilities*, *20*(3), 205-222. https://doi.org/10.1080/07263869500035561

Talbot, T. J., & Langdon, P. E. (2006). A revised sexual knowledge assessment tool for people with intellectual disabilities: Is sexual knowledge related to sexual offending behaviour? *Journal of Intellectual Disability Research*, *50*(7), 523-531. https://doi.org/10.1111/j.1365-2788.2006.00801.x

Thompson, D. (2001). Is sex a good thing for men with learning disabilities? *Tizard Learning Disability Review*, *6*(1), 4-12. https://doi.org/10.1108/13595474200100002

Thompson, D., & Brown, H. (1997). Men with intellectual disabilities who sexually abuse: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, *10*(2), 140-158. https://doi.org/10.1111/j.1468-3148.1997.tb00014.x

Thompson, V. R., Stancliffe, R. J., Wilson, N. J., & Broom, A. (2016). The content, usefulness and usability of sexual knowledge assessment tools for people with intellectual

disability. *Sexuality and Disability*, *34*(4), 495-512. https://doi.org/10.1007/s11195-016-9458-4

Thompson, V. R., Stancliffe, R. J., Broom, A., & Wilson, N. J. (2016). Clinicians' use of sexual knowledge assessment tools for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *41*(3), 243-254. https://doi.org/10.3109/13668250.2016.1164303

Thompson, V. R., Stancliffe, R. J., Broom, A., & Wilson, N. J. (2014). Barriers to sexual health provision for people with intellectual disability: A disability service provider and clinician perspective. *Journal of Intellectual and Developmental Disability*, *39*(2), 137-146. https://doi.org/10.3109/13668250.2014.898742

Vanny, K. A., Levy, M. H., Greenberg, D. M., & Hayes, S. C. (2009). Mental illness and intellectual disability in magistrates courts in New South Wales, Australia. *Journal of Intellectual Disability Research*, *53*(3), 289-297. https://doi.org/10.1111/j.1365-2788.2008.01148.x

Wehmeyer, M. L., Buntinx, W. H., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., Verdugo, M. A., & Gomez, S. C. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual and Developmental Disabilities*, *46*(4), 311-318. https://doi.org/10.1352 /2008.46:311–318

World Health Organization. (2015). Sexual health, human rights and the law. World Health Organisation.

World Health Organization. (2006). Defining sexual health: Report of a technical consultation on sexual health. World Health Organisation.

Wolfensberger, W., & Tullman, S. (1982). A brief outline of the principle of normalization. *Rehabilitation Psychology, 27*(3), 131–145. https://doi.org/10.1037/h0090973

Young. R., Gore. N., & McCarthy. M. (2012). Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study. *Journal of Intellectual & Developmental Disability*, *37*:4, 343-347. https://doi.org/10.3109/13668250.2012.704983

**APPENDIX A**

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May 2018

## Assessing Consent for Sexual Activity

Information Sheet for Participants

My name is Michelle Williams and I am a Clinical Psychology and Masters student, Psychology Department, at the University of Canterbury. I also am employed as a Behaviour Specialist at Explore Specialist Advice. The aim of this research is to inform professionals' assessments of the capacity of adult clients who have an Intellectual Disability, to gauge the presence or absence of consent for sexual activity in others. The prevalence of harmful or concerning sexual behaviour in people who have an intellectual disability is significantly elevated in comparison to people without an intellectual disability. Several authors have suggested that the reason for these high rates is a lack of sexual knowledge. However, there are also a significant number of people with an intellectual disability who have committed offences or concerning sexual acts, yet do have a satisfactory or adequate level of sexual knowledge. Experience of working in this field has highlighted the importance of understanding this, through a process of assessment.

You are invited to take part in the study and if you choose to do so, this will involve completing an anonymous online survey (you will be asked to name your profession, e.g., psychologist; but no other identifying information).

Participation is voluntary and you have the right to withdraw at any stage. To do this you can simply close the browser window. If this is done, all data previously provided by you will be removed from the study and deleted. However, because the survey is anonymous, once you have completed the survey and submitted your responses it will no longer be possible to withdraw your data, as there will be no way to identify which responses were yours.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be known in relation to your survey responses. All survey data will be stored securely in electronic format and only the research team will have access. Data will be retained for five years and then destroyed. At the end of the survey, you will have the option of providing your contact details in order to enable us to place you in the draw to win one of three $100 Westfield shopping vouchers, however this will be optional. You will also have the option of providing contact details for the purpose of receiving a summary of results of this project after it is completed. All contact details provided for these purposes will be securely stored in electronic format, separately to the survey dataset, and will be deleted once the vouchers and results summaries have been provided. Additionally, a thesis is a public document and will be available through the UC Library.

The project is being carried out as a requirement for my Masters Degree in Psychology under the supervision of Dr Sarah Christofferson, who can be contacted at sarah.christofferson@canterbury.ac.nz.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Please proceed to the survey here:

http://canterbury.qualtrics.com/jfe/form/SV_5ioyoH9rGN4VHzD

## APPENDIX B

QUALTRICS QUENSTIONNAIRE

○ I consent to participate in the study

○ I do not consent, I do not wish to participate

**What is Concerning Sexual Behaviour?** Concerning Sexual Behaviour is wide ranging and includes both contact (touching) and non-contact behaviours (grooming, exhibitionism, inappropriate sexual boundaries, voyeurism, preoccupation with sexual matters, and sexting or recording images of sexual acts). Concerning Sexual Behaviours may involve behaviours that are entirely self-focused such as excessive masturbation, or behaviours that involve others, in a non-consensual manner. These behaviours are not normative, are considered unacceptable by society and may place others at heightened risk of harm. Sexual contact with anyone more vulnerable or disabled is deemed to be concerning sexual behaviour.

**There are no wrong answers to the following; please answer according to your day to day practice and not your 'ideal' practice.** When assessing a client for concerning sexual behaviour, which of the following assessment strategies do you use, and how often do you use this strategy:

| | Never | Occasionally | Half of the time | Most of the time | Always |
|---|---|---|---|---|---|
| Interviews with Client | ○ | ○ | ○ | ○ | ○ |
| Interviews with Significant Others | ○ | ○ | ○ | ○ | ○ |
| Interviews with Support Staff | ○ | ○ | ○ | ○ | ○ |
| Psychometric Tests | ○ | ○ | ○ | ○ | ○ |
| Archives (obtaining other records such as CYF reports, NIDCA reports, medical records, etc. | ○ | ○ | ○ | ○ | ○ |
| Observations | | ○ | ○ | ○ | ○ |

Which of the following tools have you used (currently or historically) to assess concerning sexual behaviour:

- ☐ The General Sexual Knowledge Questionnaire (GSKQ)
- ☐ The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R)
- ☐ The Assessment of Sexual Knowledge (ASK)
- ☐ The Explore Sexual Knowledge Examination (ESKE)
- ☐ Other (please state which tool/s)

_____

- ☐ None: I have not used any assessment tools to assess concerning sexual behaviour

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What features determine which assessment tool you use (please tick all that apply):

- ☐ Ease of use (usability)
- ☐ Length of time to administer
- ☐ Quality of assessment information (useful)
- ☐ Access to the tool
- ☐ Validation of assessment tool

- [ ] Following the expectations/norms of my service
- [ ] Other (please list):

_____

Which sexual knowledge assessment tools do you *currently* use, and how often do you use them when assessing concerning sexual behaviour:

| | Don't Use | 25-50% of time | 51-75% of time | >75% of time |
|---|---|---|---|---|
| The General Sexual Knowledge Questionnaire (GSKQ) | ○ | ○ | ○ | ○ |
| The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R) | ○ | ○ | ○ | ○ |
| The Assessment of Sexual Knowledge (ASK) | ○ | ○ | ○ | ○ |
| The Explore Sexual Knowledge Examination (ESKE) | ○ | ○ | ○ | ○ |
| Other | ○ | ○ | ○ | ○ |

You selected 'Other'
What are the other sexual knowledge assessment tool(s) you *currently* use?

What features determine which assessment tool/s you *currently* use:

- [ ] Access to the tool/Availability
- [ ] Ease of use (usability)
- [ ] Length of time to administer
- [ ] Quality of assessment information (useful)

☐ Content of assessment tool

☐ Validation of assessment tool

☐ Other (please list):

_____

When assessing a client for concerning sexual behaviour (CSB), which of the domains do you assess (please indicate how important this domain is, and how often you assess it):

| | How important is this domain in the assessment of CSB? | | | How often would you assess this domain with the clients you see? | | |
|---|---|---|---|---|---|---|
| | Minimal | Moderate | Very | Rarely | Frequently | Often |
| Basic Sexual Knowledge | ○ | ○ | ○ | ○ | ○ | ○ |
| Public and Private Knowledge | ○ | ○ | ○ | ○ | ○ | ○ |
| Questions regarding Legalities of Sexual Activity | ○ | ○ | ○ | ○ | ○ | ○ |
| Emotions | ○ | ○ | ○ | ○ | ○ | ○ |
| Knowledge of Gaining Consent | ○ | ○ | ○ | ○ | ○ | ○ |
| Capacity to Give Consent | ○ | ○ | ○ | ○ | ○ | ○ |
| Pornography Use | ○ | ○ | ○ | ○ | ○ | ○ |

**Definition of consent:**

Consent is when someone agrees, gives permission, or says "yes" to sexual activity with other persons. To be valid, consent must always be freely given and all people in a sexual situation must feel that they are able to say "yes" or "no" or stop the sexual activity at any point. It is the responsibility of the person initiating the sexual activity to get this permission.

Much focus is often placed on a person's ability to give consent; the following questions pertain to the capacity of a person to accurately ascertain whether or not they have the consent of a possible sexual partner.

When you are assessing concerning sexual behaviour, how frequently do you consider the client's capacity to *gain* the consent of a possible sexual partner?

- 0
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

When you are considering assessing a person's understanding of *gaining consent*, which assessment methods do you currently use:

- [ ] Clinical interview (with client and others)
- [ ] The General Sexual Knowledge Questionnaire (GSKQ)
- [ ] The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R)
- [ ] The Assessment of Sexual Knowledge (ASK)
- [ ] The Explore Sexual Knowledge Examination (ESKE)
- [ ] Other (please list):

_____

For each method you use, or have used in the past, please note how well you think the psychometric tool assesses the capacity to gain consent:

| | Never used | Not very well | Somewhat | Very well |
|---|---|---|---|---|
| The General Sexual Knowledge Questionnaire (GSKQ) | ○ | ○ | ○ | ○ |
| The Socio-Sexual Knowledge and Attitudes Assessment Tool (SSKAAT-R) | ○ | ○ | ○ | ○ |
| The Assessment of Sexual Knowledge (ASK) | ○ | ○ | ○ | ○ |
| The Explore Sexual Knowledge Examination (ESKE) | ○ | ○ | ○ | ○ |

The following questions relate to The General Sexual Knowledge Questionnaire (GSKQ):
Which sections of the GSKQ do you particularly use:

- [ ] General Sexual Knowledge
- [ ] Public / Private
- [ ] Consent
- [ ] Legal Aspects
- [ ] Other _____ Sections

In what ways, if any, do you feel the GSKQ is not meeting your needs:

- [ ] Language is confusing for clients
- [ ] It is not a validated tool
- [ ] It is too lengthy to administer
- [ ] I have not received adequate training in the tool
- [ ] Pictures are too explicit
- [ ] Content is too explicit

☐ Other (please state):

_____

The following questions relate to The Socio-Sexual Knowledge and Attitudes Assessment Tool - Revised (SSKAAT-R). Which sections of the SSKAAT-R do you particularly use:

☐ General Sexual Knowledge

☐ Public / Private

☐ Consent

☐ Legal Aspects

☐ Other Sections

_____

In what ways is the SSKAAT-R, if any, not meeting your needs:

☐ Language is confusing for clients

☐ It is not a validated tool

☐ It is too lengthy to administer

☐ I have not received adequate training in the tool

☐ Pictures are too explicit

☐ Content is too explicit

☐ Other (please state):

_____

The following questions relate to The Assessment of Sexual Knowledge (ASK):
Which sections of the ASK do you particularly use:

☐ General Sexual Knowledge

☐ Public / Private

☐ Consent

☐ Legal Aspects

☐ Other Sections

_____

In what ways is the ASK, if any, not meeting your needs:

☐ Language is confusing for clients

☐ It is not a validated tool

☐ It is too lengthy to administer

☐ I have not received adequate training in the tool

☐ Pictures are too explicit

☐ Content is too explicit

☐ Other (please state):

_____

The following questions relate to the Explore Sexual Knowledge Examination (ESKE):
Which sections of the ESKE do you particularly use:

- ☐ General Sexual Knowledge
- ☐ Public / Private
- ☐ Consent
- ☐ Legal Aspects
- ☐ Other Sections: _____

In what ways is the ESKE, if any, not meeting your needs:

- ☐ Language is confusing for clients
- ☐ It is not a validated tool
- ☐ It is too lengthy to administer
- ☐ I have not received adequate training in the tool
- ☐ Pictures are too explicit
- ☐ Content is too explicit
- ☐ Other (please state): _____

Approximately how many years have you been working with people who have an Intellectual Disability:

- ○ 0 - 2 years
- ○ 2 - 5 years
- ○ 5 - 10 years
- ○ 10+ years

Approximately how many years have you been involved in working with people who have concerning sexual behaviour?

- ○ 0 - 2 years
- ○ 2 - 5 years
- ○ 5 - 10 years
- ○ 10+ years

Which profession best describes you:

- ☐ Behaviour Specialist
- ☐ Registered Psychologist
- ☐ Clinical Psychologist
- ☐ ABA Psychologist
- ☐ Speech & Language Therapist
- ☐ Occupational Therapist

☐ Other (please state): -

_____

What proportion of your role, in the past year, involves working with people who have concerning sexual behaviour?

☐ None

☐ Minority of cases

☐ 50% of cases

☐ Majority of cases

If you would like to be entered in a draw to win one of three $100 Westfield shopping vouchers, please provide your contact email below:

If you would like to receive a summary of the results of this project, after it is completed, please provide your email address below:

**APPENDIX C**

HUMAN ETHICS COMMITTEE
Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2018/19
24 April 2018

Michelle Williams
Psychology Department
UNIVERSITY OF CANTERBURY

Dear Michelle

The Human Ethics Committee advises that your research proposal "The Clinical Assessment of Concerning Sexual Behaviour" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 19th April 2018.

Best wishes for your project.

Yours sincerely

R. Robinson *pp.*

Professor Jane Maidment
Chair
University of Canterbury Human Ethics Committee